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REVIEW

A Critical Review of Clinical Practice Guidelines for Care of Transgender and Gender Diverse Children and Youth for Use by Primary Care Practitioners

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Abstract

Purpose: To examine and critique international clinical practice guidelines (CPGs) related to transgender and gender diverse children and youth and to assess the applicability of the guidelines to ethical and affirming primary care practice.

Methods: A review was conducted to obtain English language clinical guidelines. Guidelines were obtained from electronic databases, medical associations, government agencies, and community organizations. Guidelines were critiqued by all authors using the AGREE II instrument.

Results: Nine documents were reviewed. Overall, there was agreement among reviewers that the scope, purpose, and clarity of presentation of the guidelines was carried out well. Areas identified for improvement in all guidelines included clarity/rigor of methodologic development, inclusion of community stakeholders, and transparency of editorial independence. The *Endocrine Society Clinical Practice Guideline* scored highest overall. Despite lower overall scores, other guidelines were identified as having strengths of practical utility within primary care and/or in the discussion of specific social, ethical, and cultural considerations of transgender care in differing contexts worldwide.

Conclusion: The use of specific, high-quality CPGs can support primary care practitioners to provide gender-affirming care to children and youth. Methodologic improvement in the development of these CPGs is needed to ensure the best possible quality of care is being outlined.

Keywords: adolescent; child; primary health care; transgender person

Introduction

Primary care practitioners have recently seen an increase in children and youth presenting with gender identities different from their sex assigned at birth; these include youth who identify as transgender, gender diverse, nonbinary, gender fluid, and a myriad of other gender identities.[1–5] Formal education for health care practitioners around the provision of quality transgender health care has been, to date, quite limited.[6–8] Heinz and MacFarlane[9] found that 63% of participants had to teach their doctor about specific aspects of their transgender health care, with 11% expressing the perspective/feeling that their doctor was overall not sufficiently knowledgeable in this area of care. Lack of perceived competency is also echoed in qualitative research with primary care providers. Ziegler et al.[10] found that primary care practitioners strongly felt further training was needed to provide effective primary care for transgender individuals. This dearth of competency has translated to a significant incongruence between the demand for and access to care.[4,11–13]

In addition to a lack of practitioner experience and knowledge, barriers to health care experienced by transgender individuals can include marginalization, discrimination, deficiency of services, and structural

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barriers.[6,8,14] Up to 40% of transgender individuals do not have a primary care practitioner,[15] 30–40% do not utilize regular medical care,[16] and up to 50% report having foregone essential/urgent health services.[17] Access to gender-affirming health care practitioners varies considerably by geographic location.[18–20] However, even with established access to a primary care provider, a majority of Canadian youth, both rural and urban, reported significant difficulty in obtaining referrals for surgery readiness assessments.[21] In Canada, 43% of transgender and nonbinary youth reported missing out on health care for a number of reasons including previous bad experiences, fears about what practitioners would say, and concerns about forced parental involvement.[17,21] There is also considerable variability in whether services will be covered by public health care systems, private insurance, or require out-of-pocket payment. In Canada, provincial insurance covers assessment and some treatments, but components deemed "esthetic" are private-pay and often prohibitively expensive.[22]

Although the majority of transgender youth health research occurs in the United States, significant access challenges exist worldwide.[23,24] Many countries do not provide financial coverage for any component of transgender care.[25] In Latin American countries, researchers have highlighted issues with access to health care for transgender people of all ages. Barriers include a lack of knowledge and comfort providing care, difficulty obtaining legal documents that accurately reflect a person's gender identity, a lack of resources devoted to specialized care needs, and underlying social stigma against transgender people.[26] More than half of youth in an Australian survey reported having negative experiences with a health care practitioner, and a quarter avoided medical services because of their gender identity.[27] Despite clear medical consensus against reparative or conversion therapy,[28–30] people worldwide continue to report mental health care practitioners encouraging them to live as their assigned sex at birth, referring families to traditional healers to "cure" them, or being hospitalized involuntarily because of their gender identity.[25,31,32]

Transgender and gender diverse (TGD) persons need access to quality health and social support care. Compared with their cisgender counterparts, TGD persons have significant health and social risks. TGD people overall are at a higher lifetime risk of violent victimization.[33] In a recent Canadian study, 28% of transgender and nonbinary youth reported having experienced sexual assault.[21] Transgender youth are more likely to be homeless and to use substances including tobacco, alcohol, and drugs.[33–35] North American transgender youth are 2–5 times more likely to have had suicidal ideation and 3–16 times as likely to have attempted suicide.[21,33,34,36,37] Sixty-four percent of transgender and nonbinary youth in Canada report having self-harmed or seriously considered suicide and 88% reported chronic mental health issues such as anxiety or depression.[21] A similar risk was found in New Zealand.[38]

The gender-affirming approach to care

Fortunately, the importance of access to quality gender-affirming care for youth is being recognized both in Canada and worldwide.[4,13,39,40] Among knowledgeable providers, there has been a distinct shift away from the "watchful waiting" delineated in the WPATH 7 toward more active and individualized care.[2] Current international practice recommendations for TGD youth recommend an evidence-based, gender-affirming view of care, advocating a wide range of inclusive and supportive social and medical interventions. An affirmative approach includes open and developmentally appropriate exploration of patient understandings of gender and euphoric and dysphoric experiences of their gender identity. Affirmative interventions include social affirmation and transition, legal name and gender marker change, possible use of puberty blocking interventions in the early stages (Tanner Stage 2) of a youth's natal puberty, possible use of gender affirmative hormones such as estradiol or testosterone in later pubertal stages, and in some cases, gender-affirming surgeries. As part of the gender affirmative approach, the American Psychological Association also recommends supporting a child or youth who had socially transitioned to be free to re-identify with their sex assigned at birth at a later stage.[41]

Transgender adults with access to medical and social-affirming processes have been shown to have improved physical and mental health, greater perception of personal safety, higher self-esteem,[4,42,43] and quality of life.[44] Findings among youth afforded gender-affirming medical treatment, including puberty blockers, reveal similar positive findings for improved mental health; increased wellbeing[45]; reduced gender dysphoria, anxiety, and depression; improved global social, emotional, and educational functioning; and overall improved quality of life.[46] A supportive surrounding environment, particularly that of the family, is noted to be a

key factor in determining when/if a child or youth accesses gender-affirming care[47] and in supporting trans youth overall resilience.[48,49] In an age- and gender-matched study, Olson et al.[50] showed improved mental health outcomes for children who socially transition, with depression and anxiety levels that are developmentally normative ($n=73$). Young people 13–25 years of age were less likely to report experiencing severe emotional distress, suicidal ideation or attempts if they had supportive families and schools.[21,51] Similarly, in a sample of transgender youth 15–21 years of age, using a youth's chosen name at home, school, and with friends reduced depressive symptoms by 71%, suicidal ideation by 34%, and suicide attempts by 65%.[52] Having a supportive primary care provider is also a protective factor, shown to increase TGD youth's willingness to seek all forms necessary for health care.[17]

Traditionally, to access gender-affirming treatment, youth have required connection to a specialty endocrinology clinic, typically in a large urban center. Fortunately, it has been increasingly acknowledged that the provision of most gender-affirming treatment is actually well within the scope of primary care[21]; enfolding full care provision for TGD persons within a competent primary care practice can markedly improve equity of access.

Research challenges

There are significant limitations in the literature surrounding TGD children and youth, with a distinct lack of cohort and longitudinal studies.[14,53] TGD youth are often rendered invisible in data owing to the absence of two-step gender questions on surveys.[54] Research on children and youth's health meets with further barriers given issues of consent of children, youth, and parents[55–57]; institutional review board and risk concerns,[55,57,58] trust,[55,57] and inclusion; or lack of inclusion of the full spectrum gender diversity in research.[55] Internationally, research on transgender youth is further problematized by the illegality of sexual orientation and gender identity expression in at least 70 countries, 9 of which explicitly outlaw gender nonconformity.[59] Even in countries where there are protective laws, there are inherent risks for participants in transgender research; by being made visible, TGD youth risk safe work, schooling, and housing[55] and research and clinical programs risk media and community backlash.

Ethical considerations

Feinberg's[60] concept of a child's right to an open future posits that parents do not have a right to determination but rather the right to hold the child's future autonomy in trust. Parents are considered entrusted to protect the rights of the child to an open future.[11] There are many ethical considerations in the care of TGD children and youth including the autonomy over their bodily integrity,[61] right of consent,[56] parental rights of care,[11,62] protection from harm through beneficence and nonmaleficence,[58] systemic justice and fairness of access to nonstigmatizing care,[63,64] and fair access to resources.[4,65,66] Newhook et al.[13] outlined the shift from watchful waiting's focus on adult outcomes of gender-affirming care's focus on supporting the child through gender development. Newhook et al.[61] argued that the reduction of childhood explorations of gender creativity "has stifled advancements in our understanding of children's gender in all its complexity" (p. 221). Child and adolescent explorations of identity, including gender identity, is thought to be best ethically explored through a supportive and collaborative clinical relationship[39] between primary care practitioners and parents[13] using an informed consent,[56] gender-affirmative approach as outlined previously.[40]

Clinical practice guidelines

The Institute of Medicine defines clinical practice guidelines (CPGs) as "statements that include recommendations, intended to optimize patient care, that are informed by systematic review of evidence and an assessment of the benefits and harms of alternative care options" (p. 4).[67] CPGs are used as a foundation for evidence-based care.[68] In primary care, CPGs provide clear recommendations, which are evidenced, informed, and presented in an easy-to-use format.[67]

A previous critique of adult focused transgender care guidelines found that CPGs are an important support for primary care practitioners, particularly after receiving limited formal education in this area[69]; it also identified a need for further appraisal of guidelines specifically focused on TGD youth. Therefore, the purpose of this article was to critically appraise the methodological rigor and clinical utility of CPGs for the primary care of TGD youth and children.

Methods

Search strategy

In addition to "clinical practice guidelines," other search terms included standard(s) of care, guideline, protocol, best practice recommendations,[70] and blueprints.[71] The search strategy is given in Table 1. Following the database search, a further search of reference

Table 1. Search results

	Initial results	Satisfied inclusion criteria	Selected for full appraisal
Search terms			
Transgender, gender non-conforming			
Youth, adolescents, children			
Clinical practice guidelines, guideline, standard of care, blueprint, protocol, best practice			
Search source—Electronic databases	163	60	5
Search source—Grey literature	16	9	4
Total included in final appraisal			9

lists and gray literature that is literature produced from nontraditional/commercial sources such as through government, nongovernmental or nonprofit organizations, was conducted. Using the same search terms, a Google search was conducted. Further relevant documents were found from primary care organizations, medical societies, and guideline databases.

Inclusion and exclusion criteria

Inclusion criteria included documents published after 2010, written in English and addressed primary health care for TGD youth (including primary care, counseling, medical management [puberty suppression and/or hormone therapy] and surgery). Youth was defined as individuals 18 years old and younger. Exclusion criteria included documents focused on only adults, non-English documents, and textbooks. This initial database search yielded 163 documents and the gray literature search yielded an additional 16 documents. Documents from the database search were predominantly primary research in trans youth clinical practice, guidelines and guideline development documents, guideline reviews, and practice papers. Gray literature included guidelines, abstract summaries, and point-of-care resource documents. Duplicates were removed and abstracts were reviewed for relevance. Abstracts that met the inclusion criteria were selected for full review. In total nine documents were selected for full review (Table 2).

Appraisal process

The nine documents were appraised using the AGREE II instrument, a formal tool to assess the quality of practice guidelines.[72] The *My AGREE Plus* online application[73] was used to coordinate the group appraisal, allowing for individual reviews and scoring, and compilation of results. Authors represented a variety of key stakeholder perspectives including from within the trans community and primary care. Each author independently appraised the nine documents.

The AGREE II has six domains including, scope and purpose; stakeholder involvement; rigor of development; clarity of presentation; applicability, editorial independence, and overall assessment. Items were rated using a 7-point scale: 1 = strongly disagree to 7 = strongly agree.[74]

Results

Overall agreement within two points on the individual AGREE II scores was achieved on 97% of the items. Mean scores for each domain were calculated and recorded out of 100 (see Table 3 for the AGREE II scores).

The *Scope and Purpose* domain scored highest overall. All guidelines were identified as clear in articulated purpose and target user. In contrast, the domain for *Stakeholder Involvement* was generally quite low in average score; this domain focuses on the described process of consultation and collaboration with members of the target community (i.e., members of transgender community and medical/social care providers with expertise). Only one document scored over 80,[25] indicating that many CPGs lacked involvement (or description of involvement) of key stakeholders. Although six of the documents[25,26,29,75–77] did identify that persons of the transgender community were consulted in the development process, only two[25,26] explicitly outlined how their views and involvement contributed to the recommendations and guideline. To a varying degree of detail, all CPGs appeared to have been developed by authors of relevant professional expertise.

The *Rigor of Development* domain focuses on the evidence underpinning the recommendations; appraises the described system of search, critique, and inclusion of the body of supporting literature as well as the process for external review and guideline update. With no document scoring over 70, this domain rated poorly overall. All documents did link supporting evidence to recommendations as well as outline health benefits/risks, with three CPGs scoring particularly high in these specific subdomains.[29,78,79] Five documents were published in peer review journals.[29,75,76,78,80] One document[79] clearly articulated an intention and procedure for future review and update.

Scores for the *Clarity of Presentation* domain ranged considerably, from a low of 46[80] to high of 96.[78] However, all documents did present key recommendations in a clear and easily identifiable format.

Table 2. Full appraisal documents

	Title	Author/ Organization and year	Country	Source	Prepubertal care	Puberty suppression	Hormone therapy	Monitoring	Surgery	Fertility preservation	Mental health	Ethical consideration	Cultural considerations	Transition to adult care
1	*Australian Standards of Care and Treatment Guidelines for Trans and Gender Diverse Children and Adolescents*	Telfer et al. (2020)[75]	Australia	Published article	X	X	X		X		X	X		X
2	*Blueprint for the Provision of Comprehensive Care for Trans People and Trans Communities in Asia and the Pacific*	Health Policy Project, Asia Pacific Transgender Network, United Nations Development Programme (2015)[25]	United States	Online document		X	X				X	X	X	
3	*Blueprint for the Provision of Comprehensive Care for Trans People and Trans Communities in the Caribbean and other Anglophone Countries*	Pan American Health Organization et al. (2014)[26]	United States	Online document		X	X		X	X	X		X	
4	*Endocrine Treatment of Gender-Dysphoric/Gender-Incongruent Persons: An Endocrine Society Clinical Practice Guideline*	Hembree et al. (2017)[78]	United States	Published article		X	X	X	X		X	X		
5	*Guidelines for Gender Affirming Healthcare for Gender Diverse and Transgender Children, Young People and Adults in Aotearoa, New Zealand*	Oliphant et al. (2018)[76]	New Zealand	Published article		X	X		X			X		

(*continued*)

Table 2. (Continued)

	Title	Author/ Organization and year	Country	Source	Prepubertal care	Puberty suppression	Hormone therapy	Monitoring	Surgery	Fertility preservation	Mental health	Ethical consideration	Cultural considerations	Transition to adult care
6	*Health Considerations for Gender Non-Conforming Children and Transgender Adolescents*	Olson-Kennedy et al. (2016)[77]—chapter in the UCSF Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People	United States	Online document	X	X	X		X		X			
7	*Management of Transgender and Gender Diverse Children and Adolescents*	Olson-Kennedy and Forcier (2019)[79]	United States	Guideline database	X	X	X	X	X		X	X		
8	*Medical Treatment in Gender Dysphoric Adolescents*	Fisher et al. (2014)[80]	Italy	Published article		X	X	X	X	X	X	X		
9	*Standards of Care for the Health of Transsexuals, Transgender and Gender Nonconforming People, Version 7*	Coleman et al. (2011)[29]	International	Published article	X	X	X	X	X	X	X	X	X	

Table 3. AGREE II scores

	Scope and purpose	Stakeholder involvement	Rigor of development	Clarity and presentation	Applicability	Editorial independence	Overall
1	85	50	35	63	54	0	50
2	93	85	46	72	71	25	71
3	89	78	50	75	73	8	75
4	94	44	67	96	63	85	83
5	75	58	23	74	52	29	63
6	86	60	53	83	55	8	71
7	96	51	68	93	73	71	75
8	72	31	24	46	43	19	50
9	92	69	51	79	57	33	71

The domain of *Applicability* surrounds the practical integration of the guidelines into practice. The authors noted that all documents discussed barriers and facilitators to implementation. With substantial variety in amount and type, all documents included tools/charts/tables for practical and ease of use of the guideline clinically; appraisers scored two documents[25,26] particularly high in this regard.

The widest score spread among the guideline appraisal process was in the domain of *Editorial Independence*. Funding for guideline development was acknowledged by only four documents[25,29,78,79]; similarly, only four documents[76,78–80] explicitly described the identification and resolution of competing interests of the development group.

Total overall scores for the documents ranged from 50 to 83. None of the included documents scored >80 in all domains.

Discussion

CPGs are key resources for primary care practitioners to integrate transgender care into practice.[10] In this review, the *Endocrine Treatment of Gender-Dysphoric/Gender-Incongruent Persons: An Endocrine Society Clinical Practice Guideline*[78] scored highest overall. This CPG was methodologically strong, and displayed clear, applicable, and practical recommendations for gender-affirming care. Of note, in a recent study of international adult transgender CPGs, this guideline also scored the highest.[69] This CPG appears to be a valuable resource for primary care practitioners of TGD persons across the lifespan.

The *Blueprint for the Provision of Comprehensive Care for Trans People and Trans Communities in the Caribbean and other Anglophone Countries*[26] and the *Management of Transgender and Gender Diverse Children and Adolescents*[79] were the second highest scored CPGs, both scoring 75 overall with high individual scores in the scope and purpose domains in particular. Of note, the *Management of Transgender and Gender Diverse Children and Adolescents*[79] is only available by subscription limiting access and thus overall utility in primary care.

Recommendations for guideline development

To improve the development of future CPGs, we previously identified several recommendations about development and structure.[69] To ensure the rigor of CPGs, it is critical to clearly outline the process of development and support recommendations with systematic, evidence-based literature. It is also essential to include persons from the transgender community throughout all phases of the development process. Another key recommendation is for CPGs to include clear tables or tools for practitioners to easily reference.

Challenges using the AGREE II

We previously identified key challenges using the AGREE II tool to assess the quality and rigor of CPGs for transgender adults[69]; similar challenges were found assessing the children and youth guidelines. The AGREE tool grading system works well with guidelines that utilize concrete and measurable diagnostic criteria (i.e., biochemical markers). Social, emotional, and behavioral outcomes have broad ranges of expression and cannot be as clearly measured or "monitored." At times, reviewers felt required to inadequately graft AGREE criteria meant for bench science values onto social science concepts. Modifications to the AGREE tool to include criteria for the critique for psychosocial outcomes in CPGs would address this challenge.

There was limited opportunity to assess the social aspects of the guidelines using the AGREE criteria. An example is *Guidelines for Gender-Affirming Healthcare for Gender Diverse and Transgender Children, Young People and Adults in Aotearoa, New Zealand*,[76] which only ranked sixth using the AGREE criteria, but

was remarkable for the integration of culturally relevant principles in the recommendations. In this guideline, Oliphant et al.[76] used the Māori concept of health and wellbeing, Te Whare Tapa Wha, as the framework for the CPG and structured recommendations accordingly. They also integrate intersectional identity concepts, additional Māori terminology and clinical examples that highlight culturally humble practices.[76] The authors of this review highlight the potentially high utility of the full version of this guideline,[76] despite its overall lower score.

Limitations

All CPGs were individually rated by each author, with differing individual perspectives; it is thus acknowledged that weighting differences may have occurred, potentially limiting the consistency of rating data. In addition, the initial systematic electronic database search was not sufficient to capture all available and included documents; to resolve this limitation, a further search of reference lists and gray literature was conducted.[81,82] This search produced relevant background material and most notably, the Oliphant et al.[76] full version guideline. Although the authors strove to be inclusive, the heterogeneity of relevant document search terms (i.e., guidelines, CPG, standard of care, protocol, and toolkits) make it possible that there are documents in existence that would have met our project inclusion criteria but were never identified.

Conclusion

Primary care practitioners have limited education transgender health care, and more particularly for TGD children and youth. Given these limitations, primary care practitioners need access to excellent quality guidelines to support their practice. This review has highlighted some of the best available CPGs for use and areas for future improvement in CPG development. High-quality CPGs can provide evidence-informed information to the primary care provider to aid in the provision of holistic psychosocial, medical, and/or surgical gender-affirming care to TGD children and youth.

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Abbreviations Used

CPGs = clinical practice guidelines
TGD = transgender and gender diverse